

# What Social Services Offer to Patients Who Undergo Cardiac Surgery

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SPECIAL techniques for diagnosis and treatment of patients with rheumatic or congenital heart disease have developed dramatically over a relatively short time. No longer are many of these patients diagnosed solely by X-ray, the stethoscope, and the electrocardiogram in their own communities. They are referred to large medical centers which frequently are far from their homes. There they meet many different people and have new and unpredictable experiences, including undergoing a multiplicity of unfamiliar diagnostic tests and procedures relative to their heart condition. There is also, now, a much greater chance that a heart operation will be the treatment of choice.

The sobering fact that the heart is the organ involved, and that an operation may be necessary, increases the patient's and family's anxiety—already engendered by leaving home, by transportation problems, by possible family disruption, by the degree of cardiac disability, and by economic hardship. The knowledge that diagnostic and surgical techniques are available and are improving is helpful, but their comparative newness can make the hospital experience for cardiac patients frightening as well as hopeful.

To help these patients get the most constructive benefit from their experience is the responsibility of the whole staff of the hospital or medical center. What the social worker, as

part of this staff, can do has been of specific interest to me, as I have provided social services to this particular group of patients for the past 6½ years.

The Clinical Center of the National Institutes of Health, Public Health Service, is a 500-bed research hospital which serves seven separate Institutes, one of which is the National Heart Institute. The clinical investigations of the Cardiology and Surgical Branches of the National Heart Institute are primarily in the area of diagnostic techniques for evaluating congenital and acquired heart defects and in surgical techniques for treating these lesions. All patients are referred by their physicians and are admitted on the basis of the research interest of the clinical investigators. There is no cost to the patient for hospitalization or for services provided. Patients come from all parts of the United States and from many foreign countries, and they have varied economic, educational, racial, religious, and social backgrounds.

There are six social work positions in the National Heart Institute; one is that of social service program supervisor. To enable the same social worker to follow a patient throughout his hospital experience, two caseworkers are assigned to the Cardiology and Surgical Branches. This continuity of social service through a particularly stressful experience is felt to be important.

These two caseworkers carry full social service responsibility for their group of patients and therefore are an integral part of the clinical programs of both the Cardiology and Surgical Branches. They are as responsible for con-

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tributing their knowledge to the treatment of the patient group as they are for assisting the individual patient. The chiefs of the Cardiology and Surgical Branches are easily accessible to the social workers for discussion of general and specific problems. The chief surgeon, the chief cardiologist, and I collaborated in writing pamphlets which are sent to parents of children and adult patients prior to admission to the diagnostic service of the Cardiology Branch. These pamphlets are based on recognition by the Heart Institute staff that this is an anxious period for patients, and they can be prepared in advance for certain general procedures.

The social workers participate in interdisciplinary preadmission and discharge planning for certain groups of patients referred by State, national, or Federal programs such as United Mine Workers of America Welfare and Retirement Fund, Bureau of Prisons, and Crippled Children's Programs. They also take part in the medical and nursing conferences and in daily and weekly rounds. However, direct social casework services to the individual patient and family are the major responsibility of these two social workers.

Approximately 500 patients, from infants to the elderly, were admitted to the cardiac diagnostic and surgical services in 1961. Usually from 7 to 13 patients are admitted weekly, and children and adults are placed in the same nursing unit where they remain from 4 or 5 days to a month or longer. These patients can be critically ill or relatively asymptomatic. The Cardiology Branch has 18 beds in one nursing unit and the Surgical Branch has 14 beds in another unit on another floor.

From 35 to 50 percent of the patients are under 16 years of age, and are usually accompanied by one or both parents. Frequently family members also accompany the adult patients. At times parents or spouses require the most constructive social casework services if the patient is to get the fullest benefit from his medical and surgical care.

Certain periods during hospitalization for diagnostic evaluation and for surgery are likely to be more stressful for patients and their families than others. These will be described as clearly as possible in relation to what might be

happening, the problems presented by patients and families, and the ways in which the social worker can be helpful.

### **First Days After Admission**

When a patient, child or adult, arrives at the Clinical Center, he frequently has come from a distant place. He may be from another country and may not even speak English. He may have left his home and community for the first time in his life, and his social and educational experiences may have been very limited. He may be alone or accompanied by family members who may be dominating, controlling, anxious, or at times even hysterical. He may have little understanding of what to expect from the Clinical Center staff. He brings his own particular worries about his heart condition and about what the future has in store for him. He may be deeply concerned about his family and their welfare during his absence, about the stability of his job, and about his status in his family and his community. He may have had no experience or previous unhappy experiences with hospitals and medical care.

Some patients may be unable to ask questions or unable to express or show fear in order to protect their families or themselves, and some may maintain such control of their feelings that they are immobilized. There are hostile, demanding, vociferous, unit-disrupting patients, and there are the compliant, dependent, quiet, "good" patients.

Neither the child nor his parents may have anticipated separation at night, and this can be their first unhappy experience. The parents may be unable to explain this necessity or to tell the child that he is going to have tests and injections. Some children are terrified of separation from their parents even briefly, and there are those children who cannot show any kind of weakness like tears because they will incur the anger of their parents. The social worker determines the reason for these kinds of behavior and effects modification or change, if possible.

Most patients and families have some fears or anxieties when they arrive, varying from what we consider minimal to near panic; these emotions can also vary in terms of the situation at a given time. In this initial period the social

worker assesses the extent and nature of the patient's anxiety and needs. Her task is to eliminate, if possible, misunderstandings or unrealistic expectations or fears, to clarify some medical recommendations or explanations, to relieve immediate economic and other external pressures, if possible, and give supportive casework help. It is important to recognize with the patient that everybody is scared and that these feelings are natural, to assure him that he will have help as needed—that he is not alone with his troubles. When the initial supportive relationship and the assessment of the patient's needs, strengths, and weaknesses are shared with the medical and nursing staff, the staff's care of the patient enables him to react more constructively to the procedures and recommendations of the diagnostic period.

### Diagnostic Period

All patients have routine X-rays, electrocardiograms, phonocardiograms, and blood tests. Most patients have a left or right cardiac catheterization, sometimes both, and sometimes an angiogram. For these tests they go to a catheterization laboratory equipped somewhat like an operating room with the staff in green caps, masks, and suits. The patient is usually awake but drowsy, although he can be put to sleep for part of the study or for all of it. The tests are uncomfortable, but rarely very painful, and they are essentially benign. They involve putting a small catheter in the arm or leg of the patient.

The procedure is explained to the patient and his family by the surgeon from the catheterization laboratory and by the cardiologist, but this does not mean that all patients understand the procedure or are relaxed about it. They may have had previous frightening experiences with a catheterization or they may be unable to conceive of tests being done in their hearts. They may not have understood the physician's explanation because of educational limitations or emotional blocking. They may be afraid of being put to sleep or insistent that they be put to sleep. They may have varying degrees of fear of needles, bleeding, or pain. The child may anticipate separation from parents and be afraid they will not return, or this test, to the

child, may mean punishment. There may be acquiescence to authority without understanding or ability to question.

Although other factors may contribute to the anxiety of patients and families at this time, concern about what the catheterization will reveal is a primary source of anxiety. This is the test which will show more specifically the kind and degree of heart disease and determine whether or not surgery is indicated. The time during the catheterization can be particularly upsetting for the parents and family members who are waiting for the patient to return and also for the results of the test, particularly if it lasts longer than they expected or if there appear to be complications after the patient returns to his room. Some patients need to be put in oxygen tents or have intravenous feedings; some are hooked up to EKG machines or blood pressure cuffs. The level of anxiety in the family or patient sometimes prevents their understanding factual explanations and reassurances from the physician and nurse. The social worker is there to ascertain the reasons for concern and provide casework service as needed.

If there are no further tests, the patient and his family might not learn for a day or two what the results show or what the cardiologist's recommendations are. These recommendations can be (a) minimal or no cardiac problem; (b) cardiac disease not amenable to surgery and requiring continued and increased limitation of activity; (c) a serious cardiac defect for which no surgical technique is currently available; (d) a severe cardiac defect or multiple defects for which surgery is recommended but very risky; (e) a cardiac lesion correctable by present well-tried techniques and correction advised; (f) a defect in small, sometimes asymptomatic children for which surgery should be scheduled in the next 2 or 3 years; (g) a palliative procedure to help a small child grow and develop until further treatment can be undertaken.

The patients' and families' responses to any of these recommendations can be very appropriate, but because of their own emotional, social, and economic needs, some require help in understanding, in accepting, and in following the recommendations. There may be parents who cannot "give up" a sick child; children or

adults who relate their illnesses to getting love and attention or to being punished; a husband who cannot continue to tolerate a dependent sick wife or a wife who cannot tolerate an independent strong husband. The patient who has not functioned for years may face with difficulty the fact of being cured and all that it implies; other patients cannot tolerate any dependency, even minimal limitations. A patient may have been told previously that an operation is his only hope for survival; a patient may have been told by family and friends not to let anybody cut him. There are patients who have difficulty making any decision, parents having to make a difficult decision for their child, patients who relate surgery to death, and patients with realistic economic, educational, vocational, and cultural medical-social problems.

This diagnostic and decision-making period is filled with unavoidable medical unknowns to which the patients, with their varying backgrounds, their expectations, and their hopes, must relate. Social casework services can reduce some of the unrealistic aspects of their fears, help them handle some of their anxieties, and hopefully, can alleviate some of the external pressures. The aim of these services is to help patients and families to plan constructively within the limits of the medical recommendations.

### **Presurgical Period**

Patients for whom surgery is planned may either remain for surgery during their current admission or return later. The decision is based on the surgeon's opinion of the patient's cardiac status, on the surgical schedule, on the patient's blood type, on the patient's emotional and social situation, and on his wishes.

These patients are transferred or returned to a surgical nursing unit, where they may wait from 3 days to 2 or 3 weeks for the operation. The unit's staff is new to the patients; only the social worker is familiar. Most patients have some member of the family with them, at least for the day or two prior to surgery, and almost without exception the children have one or both parents.

The presence of the parents is the most supportive and reassuring safeguard that the chil-

dren can have, and much of the social worker's effort to sustain the child through this period is channeled through helping parents to maintain a calm, confident, honest, and understanding manner toward their child. This is not easy for patients or parents once the day of surgery has been scheduled. Although the decision has been made, it may have been accepted only on an intellectual basis. Many parents are ambivalent; also, parents may disagree. They wonder what and how much the child should be told, and when to tell him. Some parents cannot bear to tell even an older child anything about the operation or about any possible pain; some parents have to promise the unrealistic and the impossible; some feel the need to talk about unnecessary details with or in the presence of the child; some parents expect or demand too much from the child; some, because of their own needs and their emotional inability to handle them, cannot bear to let the child cry or ask questions; some parents cannot tolerate hostility from their child; some cannot allow an older child, particularly an adolescent, to participate in planning for the operation; and some very stable and adequate parents just don't know what to do.

It is not easy for parents to manage their own fears, their possible rejection by the child and reactivation of their own guilt, their past experiences with illness and surgery, their hostility, their ambivalence, and their fear of losing their child in such a way that the child is unaffected by parental reactions. Some parents need minimal psychologically supportive help or help with external pressures from the social worker, and some need it continuously throughout this period.

There is, of course, a real possibility that they might lose their child, but in many surgical procedures the risk is minimal, and it is vital that the parents' conception of the child's operation be based on a knowledge of the risks in the specific type of surgery required for their own child, rather than on experiences of other patients and families or on past interpretations by physicians, families, or friends.

Many of these emotional reactions are also true of adult and teenage patients, where the primary casework focus is the patient rather than his family. Such patients have many of

the same problems described in the diagnostic phase. Tension and anxiety increase as the day of surgery approaches, and one goal of the social worker is to help the patient express his anxious feelings and his hopes so that the unrealistic fears or expectations can be resolved, misunderstandings clarified, and the universality of fear recognized and understood as acceptable and normal.

These patients and their families need to mobilize as much emotional strength as possible. Their confidence in the surgeon contributes a great deal to this strength, but, in this new experience, they are nevertheless likely to feel insecure. The patients are separated from their families and are thinking of the possibility that they may not return; this increases their concern about their families' futures as well as their own. Because they must protect their families from worry about them, they cannot share their feelings with any relative, and thus they feel isolated with their fears and anxieties. Such isolation can intensify feelings of inadequacy—their being unable to do their part in order to survive surgery.

Under such stresses, many patients deny their fears; others become immobilized, hysterical, belligerent, or hyperactive. We know that patients take with them to the operating room many frightening and unrealistic thoughts; both children and adults have fantasies or disturbing nightmares relating to their concept of the surgeon and his knife. This emphasizes the need for more intensive efforts of the social worker to help these patients express their fears prior to the day of surgery.

Heart operations may last as long as 7 hours. The waiting families are aware of this, but it is a very long and tense day for them. If the social worker knows them well enough, she is able to anticipate the degree of their tension, their ways of handling this, how much supportive help they will need, and when their need will be greatest.

Particularly stressful for the family is the time when the patient—especially a child—leaves the nursing unit for the operating room. The family follows as far as possible, sometimes to the operating room door. If the child is not asleep, he may cry, and this can be a devastating emotional experience.

If the social worker has had opportunities to become familiar with the child's case, she can help the parents through the moments after the surgery door closes by constructive recapitulation of the factors influencing their decision, supportive recognition of their fears, and further clarification of their understanding of what to expect. However, if she has only superficial knowledge of the case or none at all, she can only observe the family's activities and responses, offer her services, and act according to her best judgment.

It can happen that a family arrives at this experience with unrealistic ideas of the operation or with little or no understanding of what to expect following heart surgery. One husband was under the impression that his wife's heart would be taken out of her body, put on a table, operated on, and put back. Another family member thought the patient would have to be cut in two for the surgeon to get at the heart. These are extremes, but they indicate what unrealistic and frightening thoughts these families can have.

As the operation progresses, time goes by very slowly, and tension is likely to increase. There should be periodic, supportive, brief social work interviews with the family. If there is trouble in the operating room or a change of operative plans, the family is alerted and the social worker is also informed. However, if the operation is going smoothly, the staff on the nursing unit and the family do not hear anything, and the day is long for both. When the family is told that the operation is over and the patient is all right, the social worker shares with them the release of much pent-up tension. If the family has waited with the strong certainty of imminent loss, this moment could be overwhelming.

### **Postsurgical Period**

The postsurgical period has some of the same elements of stress as the day of surgery. There is still some uncertainty about the outcome; the family sees the patient in pain, in an oxygen tent, with chest tubes, only partially awake or unresponsive. The course of this critical period of recovery can be benign or stormy, but again, families and patients differ in their responses to a specific situation.

The postsurgical room contains four beds and much necessary emergency equipment; here, the patient is completely dependent on the staff. There may be as many as four postoperative patients in the room at the same time, and there are always chances of medical or surgical crises. A patient may suddenly have cardiac arrest, which necessitates opening the chest and massaging the heart, or it may be necessary to return a patient to the operating room because of internal chest bleeding. Patients may be agitated, restless, and highly vocal, and although each bed can be closed off by curtains, the sounds are audible.

At this frightening time for patients, they can use the help of the social worker, particularly if they have no family members with them. Social workers as a rule have hesitated to enter recovery rooms because of the critical physical state of the patient, but experience has shown that patients are acutely distressed and can use supportive casework help during this period. Again, the efforts of the social worker are directed toward helping the parents and families maintain a confident and calm manner when they see the patient, since they can be anxious to all degrees—angry, resentful, hysterical, confused, tired, demanding, or immobilized.

However, even though the operation is a success and the postsurgical course benign, most patients, both children and adults, have a period of abnormal reaction about 4 or 5 days after surgery—either withdrawing or being noncommunicative, belligerent, demanding, complaining, nervous, or emotionally labile. This is difficult both for the patient and for the family, particularly for parents. The social worker and the staff, who have seen this reaction many times, can reassure patients and families with confidence that this is not scientifically explainable but that it is temporary.

The usual postoperative stay is from 10 days to 2 weeks. Children recuperate much more quickly than adults, and some leave after 1 week. Discharge is discussed with the patient as soon as possible, because this helps reinforce the idea of complete recovery. Conversely, however, this idea can be frightening or upsetting for some patients or families—because it

is inconceivable that this could occur in so short a time; because they are afraid to leave a safe medical setting; because they don't understand recommendations for limitation of activity, diet, or followup medical supervision; because they have no suitable place to go or because they don't know how they are going to get home; or because they face seemingly insurmountable medical, social, and economic problems at home. Some patients cannot accept the favorable postsurgical result because of well-grounded emotional needs. The social worker can identify the problem with patients or families, help them resolve their understanding of and feelings about the recommendations, and refer them to the appropriate community agency, if necessary.

To summarize, no given patient or group of patients will respond to these stress-producing situations in the same way and at the same period of time. Thus, there can be no clearly defined points during hospitalization at which social services are the most important; they should be available whenever needed.

At the Clinical Center the social workers giving such services to patients being evaluated and treated surgically for a cardiac defect are an integral part of the cardiology and surgical staffs as well as the Social Service Department. They are included in overall planning for the patients as well as in giving direct social casework service to the individual patient or family member, and they participate in both individual and collaborative studies. The caseworker needs to be flexible and skilled in brief contacts or on-the-spot interviewing as well as in the more structured and scheduled interviewing, and she must be constructively aggressive and responsibly available to respond to any need.

Cardiac patients for whom surgery is contemplated or performed have, in general, amazing courage and emotional strength, but it is a new and stressful experience which can be best mastered if the professional skills of the whole staff responsible for their care are used both cohesively and separately, as needed.

With such an approach it is believed that the experience of cardiac surgery will be less traumatic, and it may even become a constructive growth experience for the majority of patients.